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ABSTRACT

The fundamental question for those concerned with high quality services for people with severe disabilities is how resources can best be used to assist these individuals to live better lives. The question of how to assist in creation of better lives tests and builds leadership. Leadership involves mobilizing people's resources to make progress on difficult problems. Anyone leads when performing the activities that enable people to face and deal with the complex situations that arise when a service organization works to learn how to assist people to make better lives for themselves. This paper discusses three activities of leadership to improve service quality: (1) shaping direction through vision; (2) identifying distinctive contributions by clarifying legitimate purposes of services for people who need long-term assistance; and (3) guiding daily work on problems by defining the accomplishments of effective services. The paper seeks a vision of inclusive community, which points in a different direction than a vision of human services that meet all needs within their buildings and boundaries, and thereby provides an alternative to bureaucratic control mechanisms. (16 references) (JDD)

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# WHAT'S WORTH ASKING FOR?
# LEADERSHIP FOR BETTER QUALITY HUMAN SERVICES

by

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## Introduction

### Decisions that make a positive difference

Brian and his family rely on their community's human services because of his severe disability. Brian's recent experiences illustrate the kind of human service decisions that make a difference in the lives of the people involved.

Brian works in a restaurant cleaning the dining room, stocking the salad bar, and assisting with food preparation. At age 26, it is his first job. His mother says, "He was proud to get a name tag. He is most proud of the idea that he works like everybody else." His co-workers say he enjoys being part of their group. His employer says he does a good job, most of the time. Brian says very little, but most work days he gets up without difficulty and much of the time he does his tasks willingly and capably.

Group home staff recognize that difficult behavior, which led to his institutionalization and has frustrated their efforts at behavior management, happens less frequently since he has been working. His job coach notices that Brian seldom bites himself, swears loudly, or sucks his thumb at work and thinks it is mostly because of the influence of his co-workers and his interest in his job.

Brian is not cured. He still has significant difficulty with self control and he continues to need some extra help from his supervisor, some extra help from his co-workers, and some assistance from his job coach. He still has difficult times at the group home. If he lost his job, he would need a great deal of help to find another one.

Brian does have more satisfying days, the opportunity to be part of a work group, the chance to learn new things and earn a wage, and the status of being a worker. Those close to him have a renewed sense of a positive future for him. As his mother says, "Every year we think he has come to his full potential and he keeps on going." (adapted from Guy, Scott, Hasazi, & Patten, 1989, p. 10)

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A somewhat different version of this paper is published in V. Bradley & H. Bersani (eds.), (1989). *Improving the quality of services for people with developmental disabilities: It's everybody's business.* Baltimore: Paul Brookes.

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Community living for everyone

Jobs; not "getting ready"

Support to fit changing individual needs

Brian changes because the service providers and policy makers he relies on have changed their thinking, their policies, and their practices. Because they resolved to make community living possible for everyone, regardless of the extent of disability, Brian returned from the institution to his home community. Because they discarded the unhelpful idea that Brian was not ready to work until his behavior was under control, he has a job. Because they have learned to develop individual jobs that offer the opportunity to be part of a work group, Brian spends his work hours and his break times with people who are not disabled in an ordinary restaurant near where he lives. Because they recognize that he might want or need to change jobs, they want to maintain the capacity to support him as his circumstances change. His struggle for effective communication and self-control continues, but now in the context of greater participation in community life. With cooperation from the other people he relies on, his life changes, mostly for the better, a step at a time. His mother's life improves. And there are small, mostly positive changes for his employer and co-workers as they get to know Brian. And service staff have more demanding and satisfying jobs.

Services shape people's experience of community

The designers and providers of human services affect the daily experiences and the future prospects of the people, families, and communities who rely on them. Their policies and daily practice influence...

- ✓ where a person who depends on services lives, learns, works, and plays
- ✓ what activities fill the person's days
- ✓ who the person gets to know and where the person belongs
- ✓ the way the person and others understand who the person is

When someone depends on services for housing, necessary personal assistance, and daily occupation over a long period, as many people with severe disabilities do, services become life defining.

## Leadership for Quality

The fundamental question for those concerned with high quality services for people with severe disabilities is,

The question

**How can we use our resources to assist the people who rely on us to live better lives?**

As Brian's mother reminds us, the notion of a better life is necessarily ambiguous. Because he gets help that is responsive to his interests and needs, Brian keeps outgrowing other people's ideas of what a good life for him will be.

Openness to the question of how to mobilize resources to assist better lives causes uneasiness. Human service organizations can't manufacture better lives. People weave better lives from the resources afforded by individual effort, personal relationships, available opportunities, and help from services. So the outcomes of service to people with severe disabilities arise from collaboration between the person, family and friends, neighbors, classmates, co-workers, employers, and service providers. Frustration awaits those who desire both control of necessary services through quantifiable objectives, standard procedures, and well defined lines of accountability and assistance toward better lives for people.

Engaging ambiguity

Engagement with the question of how to assist people to live better lives increases uncertainty, the possibility of conflict, and the demand for change. But responsible policy makers and practitioners won't try to dodge the question by reducing the pursuit of service quality to conformity with external standards and regulations or by retreating into arguments about the impossibility of doing anything until science produces objective measures of "better lives." Avoiding the question reduces decision makers discomfort, but at the cost of denying the links between service practice and the realities of life for people

with disabilities, their families, and community members. Such denial cuts off policy makers and practitioners from essential information, reduces their options for effective action, and compromises the integrity of their efforts by shifting the whole burden of change to the person with a severe disability.

Leadership is...

The question of how to assist better lives tests and builds leadership. **Leadership means mobilizing people's resources to make progress on difficult problems** (Heifetz & Sinder, 1988):

...working on difficult problems

- Problems for which **definitions must be negotiated** among people with different understandings
- Problems for which **responses must be invented** rather than simply selected from a menu of proven solutions
- Problems which the people involved feel **pressure to avoid** because making progress implies personal, organizational, and social learning and change.

Activity, not position

Leadership does not flow from a position on the organization chart or an expression of personal charisma. Anyone leads when performing the activities that enable people to face and deal with the complex situations that arise when a service organization works to learn how to assist people to make better lives for themselves.

This paper discusses three activities of leadership for improved service quality. First, shaping direction through vision. Second, identifying distinctive contributions by clarifying legitimate purposes of services for people who need long term assistance. And, third, guiding daily work on problems by defining the accomplishments of effective services.

## A Vision of Inclusive Community

Vision animates and directs people's action toward a desirable future that is unlikely to happen without effort and learning. Vision describes the community circumstances in which people with disabilities can lead better lives. Judith Snow (1987, p. 1) speaks powerfully to many concerned people:

> In order to create or expand the capacity of communities to respond to their own members, it is clear that a fundamental activity of change is to welcome people with disabilities into ordinary, rich networks of relationship. To achieve such a welcome, disability and those who carry it must be seen as less threatening and burdensome, if not in fact as unusual gifts to the broader social structure. People must see that disability does not have to be fixed or cured, but accepted and challenged. The individual must be welcomed, celebrated and listened to, challenged and supported in every environment to develop every talent that he or she potentially has, just as ordinary people should be. His or her contributions must be facilitated and used for the benefit of the wider group. In short, every citizen must be an ordinary citizen.

This paper follows Judith Snow in seeking a vision of inclusive community. A vision of inclusive commmunity points in a different direction than a vision of human services that meet all needs within their buildings and boundaries would. The search for the excellent self-contained service program leaves people wandering in a blind alley; while the search for ways to build more inclusive community directs attention to the network of streets and roads that can lead to opportunities for better lives for everyone (McKnight, 1987).

Vision arises from listening

Expressions of vision arise from careful listening and thoughtful reflection on the experience and interests of the people concerned. Vision energizes by creating tension with current reality; it communicates how the people involved want things to be different. Statements of vision feel right and vital to the people concerned, even if they

may seem strange, impractical, or even foolish to others. Vision can be chosen, but it cannot be coerced. People don't finish with a vision; rather, as they work toward it, their appreciation of its meaning deepens and the words and symbols that communicate it grow richer and clearer.

The power of vision

A human service organization whose members discover and commit themselves to a common vision of inclusive community has an alternative to bureaucratic control mechanisms. People with a common vision have a sense of direction. They find it easier to face difficult situations, cooperate, deal with conflicts, create innovations, and stick with their work when things get difficult than people controlled only by hierarchial relationships do. (Bennis & Nanus, 1985).

No short cuts

The attractiveness of having a vision tempts some managers to counterfeit one by imposing a statement through administrative authority. However, there are no shortcuts. Vision can only be shapedby listening, reflecting, and learning through action. A person involved with the organization —including a person with a disability or a family member— contributes to developing vision through these simple, but difficult activities:

To develop vision...

...converse

- Invite a variety of people to describe their sense of a desirable future for people with disabilities, their families, and other members of their communities. **Listen carefully and respectfully for the kind of community people want to create to support their search for better lives.** Pay special attention to people with disabilities, their families and friends.

- Keep the conversation going beyond statements about the internal state of the person with a disability (like "being happy" or "reaching full potential"). Ask, "What would it take to increase the chances of being happy or reaching potential?"

- Critically study the thoughts of others who have considered the situation of people with disabilities and the question of developing strong communities.

...reflect

- Reflect on what people say. Think about what social

circumstances will make it possible for people with disabilities to pursue better lives. Look for common themes and vibrant images among the different answers people give. Think about whether or not conflicting answers point toward some common intention.

...communicate

- ○ Practice expressing a vision that captures and vividly communicates what people want to work toward together. Try alternative ways to clearly express vision: experiment with different symbols and media. Check expressions against other people's felt sense of a true and exciting direction.

- ○ Ask for agreement about vision, "Is this really what we want to create?" Declare personal commitment to work toward the vision.

...act

- ○ Feel the tension between the vision and current reality, "How does this vision stretch us?" "Does it test our courage to describe the distance between what we now have and what we want?"

- ○ Scan for opportunities to try behavior consistent with the vision. Keep asking, "How can we respond to this situation in a way that moves us toward our vision?"

...renew

- ○ Make time to refresh the vision by renewed listening, reflecting on how working toward the vision deepens or modifies its meaning, reaching out to involve new people, and celebrating.

## Organizational Purpose

Distinctive contribution

Vision evokes future social conditions that will make possible better lives for people with disabilities . Organizational purpose specifies the distinctive contribution a particular human service program can make to creating those conditions. Organizational purpose

- ✓ Identifies the **position** the program seeks in the lives of the people who rely on it and in their communities
- ✓ Delimits organizational **contracts** by defining the kinds of promises the program can legitimately make
- ✓ **Concentrates energy** by ruling out a number of possible courses of action
- ✓ Promotes organizational **learning** by presenting assumptions about what is possible and what is not and focusing what the organization needs to learn

Statements of organizational purpose answer the basic question from people with disabilities, their families, and their communities: "How can you help?"

Three purposes of human services for people who require long term support

These three purposes of services for people who require long term support (O'Brien & Lyle, 1987) offer a starting point for a human service organization's efforts to understand, articulate, and negotiate its purposes.

A desirable personal future

↔ **Assist people with disabilities, along with their families and friends, to discover and move toward a desirable personal future as part of ordinary community life.**

- Help people, as necessary, to define their interests and capacities, often by helping them discover, try and evaluate a variety of new experiences
- Assist in development of opportunities for people to pursue their interests in community settings, including workplaces, schools, and a home of the person's choice

- Provide or arrange the assistance, adaptions, systematic instruction, or other supports necessary for the person to use community opportunities.

A human service that accepts this purpose will...

| ...move away from... | ...move toward... |
|---|---|
| ...primary focus on people's deficiencies; treatments; & professional-client relationships | ... alliances with people with disabilities, their families, & friends |
| ...congregating people with disabilities together for service purposes | ...expressing visions of desirable personal futures, even for people who have very limited experiences or great difficulty communicating |
| ...human service owned & operated buildings | ...better incorporating necessary, skilled help with health, mobility, communication, learning, and self-control into the routines of ordinary setting |
| | ...personalizing support to match individual needs. |

Build competent communities

↔ **Offer needed help in ways that support and strengthen community competence.**

- Support, don't substitute for, families and friends who care
- Strengthen links to community networks
- Expand membership in community associations
- Increase the inclusiveness of regular classrooms, the openness of the local economy by developing a variety of jobs for people with disabilities, and the number of adults with disabilities who lease or own homes
- Improve the effectiveness and inclusiveness of the services and benefits available to all citizens
- Build alliances with people and groups concerned with improving community life.

A human service that accepts this purpose will...

| ...move away from... | ...move toward... |
|---|---|
| ...all or nothing service designs | ... sharing responsibility for providing assistance with families, friends, classmates,coworkers, and neighbors |
| ... the assumption that service providers necessarily know better than people with disabilities, their families and friends, and ordinary people who share classrooms, work places & neighborhoods with people with disabilities | ...consulting people about how they would define and solve problems for themselves |
| ...positioning the service as a charity worthy of community support because of the good it does for unfortunates | ... positioning the service as worthy of support because it builds the inclusiveness of the community |
| ... staff disconnection from community people, organizations, & activities. | ... staff involvement with community people, organizations, and activities. |

Support good experiences now

↔ **Offer needed help in ways that protect and promote valued experiences now for the people who rely on services.**

- Identify, solve, and evaluate day to day problems in terms of their impact on the quality of people's everyday experience.
- Evaluate long term investments in terms of their impact on the quality of people's everyday experience.

A human service that accepts this purpose will...

| ...move away from... | ...move toward... |
|---|---|
| ...evaluating people in terms of what they must do to get ready for valued experiences | ...determining what it would take to offer a person good experiences today |
| ... assessing experiences imposed by service providers on groups of people as "for their own good" or as "what they choose" | ...assessing experiences imposed by service providers by asking the people involved for their own evaluations and by asking "How would this seem to me if I were experiencing it?" |
| ... erecting service continuua which require people with severe disabilities to earn their way to valued experiences | ...developing policies and services that offer flexible assistance and back-up to people involved in a variety of individually chosen community settings. |

**Independence reconsidered**

Many human service policies identify independence as a central purpose. But I do not. Independence can't be an organizational purpose if it is understood as being able to do for oneself, without extra help. Most people with severe disabilities need continuing extra help and many of them rely on human services for at least part of that help. Most people's abilities can be enhanced and most people can get a substantial part of the extra help they need from family members and friends, classmates, co-workers, and other ordinary people. But a service that identifies its distinctive contribution as treating people so they will do for themselves makes a promise to severely disabled people that existing technology won't allow it to keep. An organization bound to this common understanding of independence will avoid people it is technically incompetent to serve. Of course, people unable to manage without extra help can be in charge of their own lives. Most people with severe disabilities can set goals for themselves and express preferences about the way they want to live. Many people with severe disabilities can supervise their helpers. Human service policies and practices can promise people with severe disabilities assistance in pursuing a desirable personal future and backing to control their own lives.

## Barriers to clarifying & negotiating organizational purpose

When the people who rely on a human service experience severe disabilities, defining and negotiating organizational purpose is problematic for three reasons: the uncertainty of technology, the endurance of prejudice against people with severe disabilities, and the rigidity of most available human service funding.

**Uncertain technology**

- The effects of available technology are uncertain. Most people with severe disabilities can expect significant help with mobility, health, communication, productivity, and learning new things.They can expect the people who assist them in these areas to continuously improve the effectiveness of assistance (Snell, 1988). But cure lies beyond reasonable expectation and this complicates discussion of purposes. Some people find it hard to value activities that open

opportunities and offer support to people without promising some form of technical fix. Some people find it easier to cope with the impression that a person with a severe disability should accept fate than with the fact that real change can happen but not cure. Some people with professional skills find it difficult to acknowledge the limits of their expertise and authority.

Prejudice & Exclusion

- People with severe disabilities face ingrained social prejudice which results in their exclusion from everyday life. The prejudices that justify exclusion control many people's thinking about what makes sense for people with disabilities. Confronting prejudice means challenging and changing arrangements that many people believe make so much sense that alternatives seem absurd or unthinkable.

  - In an environment shaped by exclusion, it has come to make sense to leave people with disabilities out of ordinary classrooms, workplaces, and homes until their disability has been repaired by heroic individual and professional efforts in a succession of carefully graduated service environments (Taylor, 1988).

  - In an environment shaped by exclusion, it makes sense to assign full responsibility for all of the effects of prejudice and service failure to the person with a disability and to redefine collective failure in medical terms as individual chronicity (Ferguson, 1988).

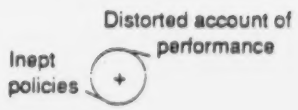
There is no reliable technology for engineering changes in community life, or, for that matter, within service settings. Shifting the social patterns that exclude and blame people with severe disabilities requires person to person, setting by setting effort. Worse yet, service policy makers and providers who want change in community practices and attitudes encounter the necessity of confronting and changing themselves as their efforts at changing community members become entangled in the constraints of their own system. Many service policy makers and provid-

ers experience understandable reluctance to assume purposes which call for so much change.

Funder impositions

- Most funders don't pay to assist people to lead better lives; they pay for slots, seats, beds, placements, active treatment, or preparation for competitive employment. A growing proportion of service providers are virtually wholly owned subsidiaries of funding sources which impose purposes and procedures. Many service managers rightly believe that personal and organizational survival depends on carrying out the funder's purposes and requirements, as defined by the funder's agents and monitors. And when funder expectations vary from local experience, fear of failure drives providers to act as if the emperor is fashionably dressed. As one residential provider said,

A vicious circle:




> *People are supposed to flow from here to independence because of the training programs we run. That doesn't work for the people here. Just because they need some personal attendant care, they are stuck here. And all the training programs we run aren't going to change that enough to make a difference. But [the system] doesn't care about that. They don't want to hear. All that matters to them is that we are recording enough hours of active treatment every day to keep the money flowing. That makes a big part of our job a joke.*

This leaves policy makers with a distorted picture of the situation they manage and providers with little incentive or energy to explore and negotiate purpose.

Leadership through purpose

Effective leadership clarifies and strengthens purpose by focusing the organization's energy on fulfilling promises it can keep that will assist people to lead better lives. Anyone involved with the organization can exercise leadership in clarifying purpose by assisting people in the organization to deal with these complex issues:

Clarify what the organization can do

- Spend time thinking about the distinctive contribution this organization can make to building the social conditions necessary for people with disabilities to lead better lives. Consider what people with disabilities and their families and friends want for themselves and identify how the organization can assist. Gather information about what other organizations are doing to assist the people who rely on them. Think about what it is reasonable to expect from the available technology and clearly describe its present limits. Express the results of all this thinking in a clear statement of organizational purpose.

- Select people who are likely to have trouble understanding the organizational purpose statement and figure out how to explain it to them and get their comments.

Debate purpose

- Select people who are likely to oppose the organizational purpose statement and understand the reasons for their opposition. Look for ways to negotiate their agreement without compromising the organization's purposes.

Define professional roles

- Look closely at expectations the organization has for professional people. Avoid pushing professionals into the role of magician by making them responsible for resolving situations which in fact can only be addressed if everyone involved joins in working together. Times when people feel disappointed with professionals are good times to reconsider ways to take shared responsibility.

- Limit the authority the organization offers people in professional roles to areas of their legitimate competence. Expect professional work to contribute to rather than control organizational purpose: remember, the organization exists to help people define and pursue better lives; professional assistance is one of the means to that end. Expect professionals to join discussions about organizational purpose and individual people's futures as equals with other concerned people. Expect professionals to sometimes say, "I don't know; let's work on it together." Enable professionals to keep up with the rapid growth of knowledge in their field. Times when

people feel resentful of professionals are good times to renegotiate expectations.

Test organization in terms of purpose

- Learn to read the purposes the organization communicates through its settings and processes (Williams & Tyne, 1988). Recognize, call attention to, and work to change the ways the organization expresses social prejudices against people with severe disabilities ( Wolfensberger & Glenn, 1975; Wolfensberger & Thomas, 1983).

- Examine the assumptions and procedures that shape the way the organization makes decisions about people with disabilities. Closely challenge the relevance, the limitations, and the costs of testing procedures, entrance and exit criteria that control access to opportunities, and record keeping. Ask, "Does our decision making focus attention on people's capacities as well as their deficiencies?" Ask, "Does our decision making value personal knowledge at least as much as professional conclusions?" Ask, "How does decision making about individuals change the way we use program resources?"

- Pay attention to complaints about the ways funding arrangements, system regulations, and policies block efforts to assist people to lead better lives. Look for ways to satisfy requirements and do what's necessary; negotiate with funders and regulators for waivers or reinterpretations of rules to permit action; improve policy maker's information about system barriers by collecting and communicating information about what people want to do that is otherwise likely to be hidden from them; and support efforts to change counterproductive policies.

Invest in purpose

- Shift resources toward activities that support organizational purposes as rapidly as possible.

## Service Accomplishments

A clear vision of an inclusive community sets direction. Organizational purposes identify the distinctive ways a human service organization contributes to building inclusive community by assisting people with severe disabilities to discover and pursue desirable personal futures in ways that support valued experiences. Clearly defined accomplishments guide daily work in terms of purpose and vision.

Continuous improvement

Making progress toward the vision depends on continuous improvement in capacity to manage the problems created by assisting people with severe disabilities to take their place in community life. Service accomplishments set boundaries on solutions to the stream of problems that arise as leaders align service resources with people's desires for a positive future.

Progress on problems comes through a cycle of work in which a person with a disability, family and friends, and service staff define steps toward a desirable personal future, identify opportunities for and obstacles to taking these steps, involve other people as necessary, plan and take action to develop opportunities and supports, negotiate the conflicts arising from action, review what worked and what didn't work, and identify the next step. **Maintaining and allocating resources through this cycle, over time and in harmony with vision and organizational purpose, creates good quality services** (Deming, 1986).

Define steps toward a desirable future
Identify obstacles & opportunities
Involve others
Act to create opportunities & provide support
Negotiate conflicts
Review what worked & what didn't work

Accomplishments support valued experiences & build community competence

Five closely linked service accomplishments focus and guide service staff in their work. Accomplishments describe worthy consequences of service activities. Accomplishments don't prescribe how service staff should behave; they clearly identify results worth the costs of producing (Gilbert, 1978). Each accomplishment supports a vital dimension of human experience which common practice limits for people with severe disabilities. These interdependent qualities of experience include:

Valued experiences

- ✚ Growing in relationships
- ✚ Contributing
- ✚ Making choices
- ✚ Having the dignity of valued social roles
- ✚ Sharing ordinary places and activities.

Each accomplishment challenges and strengthens the relationship between people with disabilities and other community members.

Assisting people to grow in relationships

→ A human service program focused on **community participation** will mobilize its resources to assist people with severe disabilities to form and maintain the variety of ties and connections that constitute community life.

- A growing number of people with severe disabilities will know and be known by non-disabled neighbors, fellow students, and co-workers; form acquaintances; get in contact with others who share an interest; make friends; share intimacy; join a variety of community associations and enjoy the responsibilities and benefits of membership; and participate in civic, cultural, and political life (Ordinary Life Working Group, 1988).
- People have the help they need to keep in touch with family members or friends from their past.
- While many people with disabilities will choose friendships and association with other people with disabilities, services will not impose congregation with people with disabilities as a condition of service.

**The challenge: Interdependence**

Building community participation challenges all people to live interdependently.

**Assisting people to contribute**

→ A human service program focused on **supporting contribution** will mobilize its resources to assist people with severe disabilities to discover and express their gifts and capacities.

- A growing number of people with severe disabilities will contribute to others' learning, enjoyment, and well being as companions, fellow students, team mates, co-workers, and associates.
- People will have the help they need to explore their interests and capacities, to develop skills, to preserve health and mobility, to communicate effectively and confidently, and to increase self-control and attention.

**The challenge: Development**

Facilitating everyone's contribution challenges all people to invest in recognizing and developing human resources.

**Assisting prople to exercise choice**

→ A human service program focused on **promoting choice** will mobilize its resources to assist people with severe disabilities to increase control over their own lives.

- A growing number of people with severe disabilities will set goals that are personally meaningful, express personal preferences, and manage the assistance they receive.
- People unable to make decisions for themselves because of age or extent of disability will have a strong personal relationship with a guardian who manages only those areas of life in which the person is incompetent.
- People will have the help they need to express their preferences, define personal goals, and try to attract the support they need from others to pursue their goals.

- People will get necessary assistance to interpret their environment, to understand other people's expectations and conditions for cooperation, to figure out satisfying ways to pursue what they want, to communicate effectively, to negotiate conflicts, to limit risks, and to manage the good and bad consequences of their decisions.

The challenge: Resolving conflict

Promoting choice challenges all people to creatively resolve conflicts.

Assisting people to experience dignity

→ A human service program focused on **encouraging valued social roles** will mobilize its resources to assist people with severe disabilities to experience the dignity and status associated with positively regarded activities.

- A growing number of people with severe disabilities will take their place and be recognized as good neighbors, contributing classmates, active members, friends, home owners, productive wage earners, and good citizens.
- People will get necessary assistance to locate and fill valued social roles in community settings, meet or change the ordinary expectations of other people in the settings, deal effectively with prejudiced or stereotyped responses from others, and present themselves positively.
- Human service programs will pay rigorous attention to eliminating stigmatizing effects of their own practices (Wolfensberger & Thomas, 1983).

The challenge: Giving up stereotypes

Encouraging valued social roles challenges all people to discard stereotypes; see other people as as individuals; and repair the damage done by past prejudiced treatment.

**Assisting people to Share ordinary places**

→ A human service program focused on **community presence** will mobilize its resources to assist people with severe disabilities to share the ordinary places and activities of ordinary community life.

- A growing number of people with severe disabilities will use a growing variety of ordinary community settings at the same time and in similar ways to other citizens.
- People will get necessary assistance to identify useful or enjoyable community settings, to get to and from a variety of ordinary places safely, and to participate effectively.

**The challenge: Inclusion**

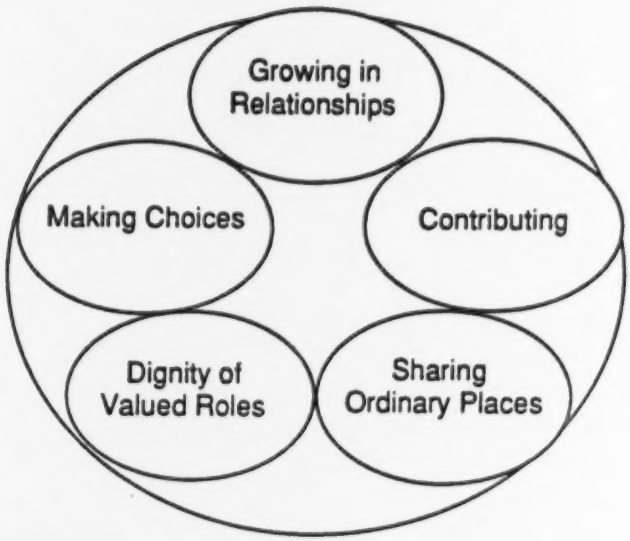
Increasing community presence challenges all people's willingness to include everyone.

**The relationship of service accomplishments to valued experiences:**

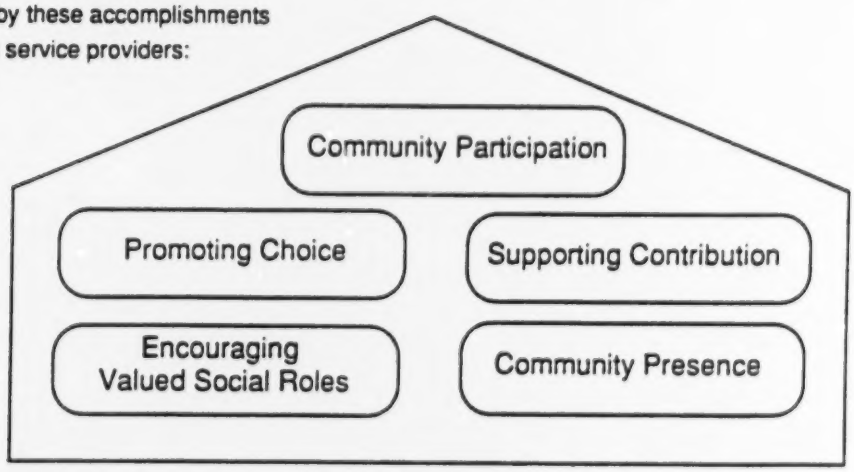
→ ✚

The diagram on the next page summarizes the relationship between valued experiences for people and service accomplishments.

Valued experiences for people:




Are created by peoples own efforts and the efforts of friends, family and communinty members, and are assisted by these accomplishments of human service providers:



## Emotional pressures to avoid accomplishment

The challenges of assisting people with severe disabilities to discover, take, and keep their place in community life present messy problems which require many cycles of action and reflection. The work makes emotional demands: people face the demands of close personal contact as well as failure, resistance, rejection, and disappointment. As emotion increases, the pressure grows to avoid work by fragmenting or denying responsibility, blaming, underestimating what is possible, avoiding information about the effects of action, waiting for a magic solution, or ritualizing (Menzies, 1959). As time goes by and complexities and emotional pressures grow, people working on a better future can easily loose track of where they set out to go. In such a complex, highly charged situation, anyone exercises leadership who involves people in these activities.

## Leadership for Accomplishment

- Spend time listening to people with disabilities, and their families and friends about their past, their interests, concerns, and sense of future. Listen to people as individuals and bring people together to talk as a group. Include people who are isolated from family and friends and people who have difficulty communicating. Profile the person's life by describing the way the person experiences relationships, contribution, choice, status, and ordinary community places. Record the images and ideas about the person's capacities and interests and verify the record with the person and family and friends. Use such expressions of vision for the person as a guide and a check on the focus of service.

- Develop opportunities for people to pursue their interests in community activities and associations. In developing opportunities, work on offering people more of each of the valued experiences. Find opportunities that offer access to more ordinary places, give people the chance to meet people, offer the person a choice, fit the individual's capacities and interests, and provide a valued social role.

- Practice reversing typical service patterns: instead of listing ways the person should change, identify opportunities and supports that would offer the person new, positive experiences; instead of gathering information about the person, gather information about the community; instead of controlling the person, give the person control.

- Carefully evaluate the organization's capacity from the point of view of the five service accomplishments. Ask the people who rely on the program and their families and friends to evaluate the program's effectiveness in promoting choice, status, contribution, presence, and relationships. Plan and negotiate ways to reallocate resources to increase capacity.

## Conclusion

Developing high quality human services for people with severe disabilities demands active engagement in complex, emotionally charged, ambiguous situations. It calls for reallocation of service resources, working outside traditional boundaries, and renegotiation of the service's position in community life. This essential work calls for the motivation arising from a vision of inclusive community, the boundaries set by a clear and realistic sense of organizational purpose, and the focus offered by well defined service accomplishments. It requires effective leadership from service workers, people with disabilities, and their families and friends if all those concerned are to face the difficult problems of creating high quality services and to make progress toward resolving them.

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